OMB SUPPORTING STATEMENT

National Survey of Organ Donation Attitudes and Practices

Submitted by:

Division of Transplantation Healthcare Systems Bureau Health Resources and Services Administration 5600 Fishers Lane Rockville, Maryland 20857 B. Collection of Information Employing Statistical Methods

1. <u>Respondent Universe and Sampling Methods</u>

A household-based telephone survey (including both landline and cell phones) will be conducted to collect data on public opinion regarding various issues related to organ donation. The respondent universe for this survey will consist of all U.S. adults (18 years of age or older). The goal is to complete a total of 3,250 interviews consisting of approximately (i) 1,250 interviews with general adult population (of all race/ethnicity groups) and (ii) additional 500 interviews with each of the four minority groups (African Americans, Asians, Hispanics, and Native Americans). The oversampling of the minority groups (by completing additional 500 interviews for each group) will be undertaken in order to carry out separate analysis of data pertaining to these specific sub-groups.

The 1,250 interviews with the general adult population will be obtained using a RDD (Random Digit Dialing) telephone sample including both landline and cell phone numbers. For the purpose of completing the targeted number (500) of interviews with African Americans, the Gallup Panel (to be described later) will be used as the sampling frame. The oversampling of the other three groups (Asians, Hispanics, and Native Americans) will be carried out by recruiting respondents from the Gallup Healthways Well-Being Index (WBI) survey (to be described later).

In the previous administration of this survey, the oversampling of the minority groups was done using RDD telephone sample by oversampling specific telephone exchanges that were expected to include a relatively high number of these sub-population groups. As noted above, the oversampling for this current survey is based on using the Gallup Panel and/or the Gallup Healthways Well-Being Index (WBI) survey. The strategy involving the use of the Gallup Panel or the WBI survey is proposed in view of the overall cost and efficiency for generating these oversamples. Moreover, targeting telephone exchanges with relatively high representation of these minority groups in a RDD survey is not a feasible strategy for cell phone sampling since information at the exchange level for cell phone users is not available. In the previous round, cell phones were not included in the sample and so this particular problem (of not being able to target specific exchanges for oversampling) was not encountered. In view of the above, the strategy of using the Gallup Panel and/or the WBI survey for oversampling the minority groups is now considered optimal for this survey.

General Adult (18years of age or older) Population Sample

Sample Design. The sample design for completing 1,250 interviews with the general adult population will be based on a Random Digit Dialing (RDD) telephone sample. The universe will consist of all adults (age 18 years or older) living in households with working telephone numbers (landline and/or cell phones) across the 50 states and the District of Columbia. A list-assisted RDD method as proposed by Casady and Lepkowski (Casady, R.J. & Lepkowski, J.M. (1993): Stratified telephone survey designs. *Survey Methodology*, 19, 103-113) will be followed for sampling of landline telephone households. A specific sampling method will be used to ensure a reasonably high hit rate without creating any significant non-coverage problems. Specifically, a

telephone number in the United States is 10 digits long (AAA-EEE-XXXX), where the first three digits are the area code, the second three are the exchange, and the last four digits are the number within the exchange. The area code, three-digit prefix and the first two digits of the four-digit suffix specify a 100-bank containing 100 telephone numbers. In the proposed Casady and Lepkowski (1993) method, this frame (Telcordia frame) of all possible telephone numbers (containing both listed and unlisted numbers) is stratified into two strata: a "high-density" stratum consisting of 100-banks with at least three residential numbers, and a "low-density" stratum consisting of all the remaining numbers in the Telcordia frame. In order to ensure a relatively high hit-rate, sampling will be restricted to the high-density stratum, i.e., to all 100-banks with at least 3 listed residential numbers.

Once a household is selected, one adult from all adults living in the selected household will be chosen at random using the "most recent birthday" method (O'Rourke, D. & Blair, J. (1983)). The "most recent birthday" method asks for the eligible person (18 years of age or older) within the sampled household who, at the time of respondent selection, has the most recent (last) birthday. The "most recent birthday" method represents a random selection of eligible household members and is considered much less intrusive than the purely random selection method or grid selection that requires enumeration of all household members to make a respondent selection.

The cell phone sample of telephone numbers will be drawn separately from the dedicated (to cell phones) telephone exchanges. Cell phone numbers are assigned to certain 'dedicated' telephone exchanges that are separate from those containing the landline telephone numbers. For the purpose of sampling cell phone numbers, these "dedicated" exchanges will be used as the sampling frame. For respondents reached on cell phones, there will not be any additional stage of sampling (like the within household sampling for landline sample). The person answering the call will be selected if he/she is found otherwise eligible for the survey. The sampling frames for both landline and cell phones (defined in terms of telephone exchanges) will be stratified by geographic region (Census region) and sampling will be done independently within each stratum. Census regions are groupings of states and the District of Columbia (DC) that sub-divide the United States for the presentation of Census data. There are four Census regions: Northeast, Midwest, South and West. The definition of these regions in terms of states is provided below.

Northeast: Connecticut, Maine, Massachusetts, New Hampshire, Rhode Island, Vermont, New Jersey, New York, Pennsylvania.

Midwest: Illinois, Indiana, Michigan, Ohio, Wisconsin, Iowa, Kansas, Minnesota, Missouri, Nebraska, North Dakota, and South Dakota.

South: Delaware, District of Columbia, Florida, Georgia, Maryland, North Carolina, South Carolina, Virginia, West Virginia, Alabama, Kentucky, Mississippi, Tennessee, Arkansas, Louisiana, Oklahoma, and Texas.

West: Arizona, Colorado, Idaho, Montana, Nevada, New Mexico, Utah, Wyoming, Alaska, California, Hawaii, Oregon, and Washington.

Sample size across strata will be based on proportional allocation and the initial sample sizes will be large enough to yield the required number (1,250) of interviews nationwide. Out of the 1,250 interviews to be completed, the split between the number of landline and cell phone interviews will be determined based on latest available estimates of the proportion of adults with access to cell only, landline only and both (dual users) at the time of finalizing the sampling plan.

Currently, that would imply roughly a 60percent/40percent ratio of landlines to cell phones in terms of completed surveys.

African American Oversamples

Sample Design. The sample for completing about 500 telephone interviews with African Americans will be based on the Gallup Panel. The following provides a description of the Gallup Panel. The Gallup Panel recruitment began with an RDD sample of telephone numbers, including both land line and cell phone samples. Following a list-assisted telephone sample design, a telephone sample representing the U.S. national population was obtained. Once the random sample was obtained, Gallup's interviewers called those numbers following an approved calling protocol and recruited members for this panel. This process is repeated to ensure continuous recruitment for the panel. Currently, the panel includes 47,514 households containing about 66,421 individuals. Respondents take a short survey about Presidential approval and other current event topics, and are asked if they would be interested in participating in additional surveys as a member of the Gallup Panel. Unlike opt-in panels, the recruitment process for Gallup panel starts with a random sample of telephone numbers and, as a result, it is possible to derive the selection probability and hence the sampling weight for each respondent on the panel. There is no time commitment to membership in the Gallup Panel. Rather, households and individuals are encouraged to remain members as long as they are willing and interested. Surveys are administered by an interviewer (over the phone) or are self-administered (either by mail or Web, depending on the Internet accessibility of the respondent). There are no financial incentives for participating in the Gallup Panel, although several token thank-you gifts are sent throughout the year. As with any longitudinal design, Gallup's Panel is also affected by attrition. Significant efforts are taken to retain panelists for as long as possible. Gallup's panel also performs very well in terms of eliminating "professional" respondents who tend to volunteer for most of the opt-in panels.

As mentioned above, the Gallup Panel will be used as the sample source for completing the oversample of African Americans. All Panel participants have been fully screened and a substantial amount of background data have already been collected (e.g., health and well-being, socio-economic and occupational status, media usage, political views, age, gender, race, ethnicity, etc.), permitting rapid sub-sampling of subjects based on demographic or experiential characteristics in the Panel database. As a result, it will be easy to identify the group of African Americans included in the Gallup Panel. The list of all African American panel members will constitute the sampling frame and an adequate number of panelists from this frame will be sampled to complete the required number (500) of interviews from this group. This sampling frame of African Americans may be further stratified by relevant variables like geographic region (Census region, for example) to ensure adequate representation from each region.

Precision of Estimates. The precision of survey based estimates will depend on sample size and also on the type of estimates. For this survey, the population parameters of primary interest will be unknown population proportions like proportion of U.S. adults who, for example, are likely or very likely to have their organs donated or the proportion of U.S. adults who support or strongly support organ donation. At the national level, based on the total RDD sample size of about 1,250, the sampling error associated with estimates of the population proportion P (proportion who say

that are likely or very likely to donate their organs) is estimated to be around 2.8 percent ignoring any design effect and under the most conservative assumption that the unknown value of P is around 50 percent. The design effect for the RDD part of the sample is expected to be minimal. Assuming a design effect of 1.25, the estimated sampling error is around 3 percent. Based on the 2005 survey, the survey based estimate of P is 78 percent. Using that as an estimate of P (instead of 50 percent), the sampling error for estimation of P, assuming a design effect of 1.25, will be about 2.6 percent. For the purpose of generating national estimates, it is also possible to combine the 2,000 interviews obtained from the minority groups with those obtained from the RDD survey. The design effect associated with this sample of 3,250 completed surveys may be relatively high because of the oversampling of the minority groups. Based on a design effect of 2.5, the sampling error for estimation of P is expected to be around 2.3 percent (assuming P=78 percent). With a design effect of 3, the sampling error will be around 2.5 percent.

For estimation of P for the African American group, the sample size will be 500. Assuming a maximum design effect of 1.25, the sampling error for the group of African Americans will be less than 5 percent even under the most conservative assumption of P=50 percent. Based on 2005 survey, the survey based estimate of the proportion of U.S. adults saying that they would be likely or very likely to donate organs is 64 percent for African Americans. Hence, the expected sampling errors are likely to be even smaller. It also will be possible to include the completed interviews with members from the African American group from the RDD survey with those from the Gallup Panel to increase the overall sample size and thereby reduce the sampling error.

Weighting of Sample Data. The sample data (the RDD sample and the African American sample based on the Gallup Panel) will be weighted to minimize bias in the survey based estimates. The weights will be necessary to correct for unequal selection probability and also to adjust for the effects of non-response. Sampling weights will be attached to each survey record and the final weight assigned to any case will be the product of the weights generated at several stages of the weighting process.

For the RDD part of the survey, the first step is to construct the base-weight that is equal to the inverse of the probability of selection. This is to correct for unequal selection probabilities of the different units in the sample. The sampling fraction used for landline and cell phone sampling will be different, leading to unequal selection probabilities. Within the landline sample, the difference in the number of residential telephone lines reaching different telephone households will cause unequal selection probabilities at the household level. Besides the selection of households, there is another stage of selection of members within the selected households (for the landline sample). We are proposing to select one adult person within the household so the overall selection probability of adult respondents will also depend on the number of adults living in the sampled household. As a result, the final selection probability will be unequal across respondents.

The weighting process will also include adjustments for the overlapping dual frame design (landline and cell phone samples) that will be used for this study. We will follow Kennedy Courtney (*Public Opinion Quarterly*, Vol. 71, No. 5 2007, pp. 750–771) to carry out this step. Basically, the proportion of respondents in the following four categories will be adjusted: (i) landline only users; (ii) cell only users; (iii) dual users – cell phone mostly; and (iv) dual users –

not cell mostly. Post-stratification weighting will be carried out to make the final sample reflect the population it is intended to represent. A separate non-response weighting step is not proposed because sufficient data about the non-respondents will not be available in a RDD telephone survey. Post-stratification is a way of improving estimators by proper utilization of ancillary information. Within suitably chosen geographic regions (Census Regions, for example), cells will be formed by crossing different levels of important variables like age, gender and race. Necessary ratio type adjustments will be done to achieve the target proportions (or counts) in all the cells. If necessary, raking-type algorithms will be used. The target proportions (or counts) will be based on known values of the corresponding population parameters. The target numbers will be available for the different post-stratification cells from latest Census or Current Population Survey (CPS) results.

The basic weighting steps for the African American oversample based on the Gallup Panel will be similar. As mentioned before, the Gallup Panel is a probability panel and hence each panel member on the sampling frame (for sampling of any minority group) will have a 'panel weight' associated with it. The probability weight assigned to any sampled unit for the African American sample will be the product of the (i) 'panel weight' and (ii) the inverse of the selection probability of the unit in the African American sample to be drawn from the Gallup Panel. The next weighting step for the African American sample will consist of weighting adjustments for survey non-response. Unlike in the case of the RDD sample, a significant amount of information on demographic variables (like age, gender, race, ethnicity etc.) will be available for non-respondents. As a result, it will be possible to construct suitable non-response adjustment cells and correct for any bias due to non-response. Finally, if necessary, an additional post-stratification weighting step will be used to make the final sample reflect the population it is intended to represent. The target data for post-stratification weighting, if used, will be obtained from Census or CPS results for the African American group.

Non-response Analysis. Survey based estimates for this study will be weighted to minimize any potential bias that may be associated with unit level non-response. For the RDD part of the survey, not much information about the non-respondents will be known. However, the distribution of demographic characteristics among respondents will be compared to latest distribution of those characteristics based on Census or CPS data. If certain demographic groups appear to be under or over represented in the sample of respondents, then those demographic variables can be used for post-stratification weighting if they are not already included. In addition, the respondents to the RDD part of the survey may be split into two groups: (i) early or 'easy to reach' and (ii) late or 'difficult to reach' respondents. The total number of calls required to complete an interview will be used to identify these groups. These two groups will be compared based on their responses to selected survey questions. This comparison will also be based on the assumption that the latter group may in some ways resemble the population of non-respondents. The goal of the analysis plan is to assess the nature of the non-response pattern in the survey.

For the African American samples based on the Gallup Panel, a significant amount of information will be available from the panel data for both respondents and non-respondents. As a result, it will be possible to examine the non-response pattern within various demographic subgroups and, on that basis, construct suitable non-response weighting adjustment cells using

variables that are available for both groups. If found necessary, a comparison of 'early' and 'late' respondents can also be carried out for the African American samples.

Asian, Hispanic, and Native American Oversamples

Sample Design. Gallup will complete about 500 interviews each with Asians, Hispanics, and Native Americans nationwide. The universe for these studies will be comprised of all adult Asians, Hispanics, and Native Americans in the U.S. The data collection will be conducted using a telephone sample design including both landline and cell phones.

For Asians, Hispanics, and Native Americans, as noted earlier, Gallup will use one of its ongoing RDD surveys, the Gallup Healthways Well-Being Index (WBI) survey, as the sample source. Given the extremely low expected incidence rate of Native Americans and Asians in the general U.S. population and relatively low incidence rate of Spanish speaking Hispanics in the Gallup Panel, this proposed strategy is an optimal way of achieving oversampling of these minority groups. The WBI is conducted in English and Spanish and is thus a useful sampling frame for Hispanics, unlike the Gallup Panel which is an English-only panel. Therefore, the WBI will be used for sampling Hispanics rather than the Gallup Panel to include the Spanish language speaking population.

For the WBI survey, Gallup interviews 1,000 adults nationally by telephone using a list-assisted RDD telephone data collection methodology. This happens seven days a week and excludes only major holidays. Survey respondents are asked a series of questions associated with well-being across a range of income and health status conditions.

The WBI survey methods rely on live (not automated) interviewers and use a dual-frame RDD sampling that includes landlines as well as wireless phone sampling to reach those in wireless-only

households, and a random selection method for choosing respondents within a sampled household. Each sampled number is called up to 3 times to complete an interview.

The WBI survey asks respondents demographic questions including questions on race and ethnicity. The respondents are also approached for permission to call them back at a later date, if necessary. The response to the race question will be used to identify Asian, Hispanic, and Native American households. This set of prescreened eligible households with permission to call back will constitute the initial sample for this task. Sufficient numbers of prescreened cases (respondents saying that they are Asians, Hispanics, or Native American on the WBI survey) will be available to generate 500 completed surveys for each group. If necessary, additional respondents (respondents reporting 'Other' race) may be added to this initial pool and then screened for Native Americans. The second stage sample to be drawn from these pre-screened cases will be stratified by geographic region and other relevant stratification variables to make the sample more representative of the Asian, Hispanic, and Native American population. The samples will also have a much higher hit-rate (proportion of Asians, Hispanics, and Native Americans in the sample) and will allow Gallup to complete 500 interviews with each group in a relatively short time period. It is anticipated that these tasks can be undertaken at the same time

the main survey is administered. That may be important for comparability of results between these groups and the overall U.S. population and the African American oversample covered in the main survey.

While the Gallup WBI survey will be used for the oversampling of Asians, Hispanics, and Native Americans, the Gallup Panel (described above) will also be available in case it becomes necessary to use any of its special features for these tasks.

Precision of Estimates. The precision of survey based estimates will depend on sample size and also on the type of estimates. For this survey, as mentioned before, the population parameters of primary interest will be unknown population proportions like proportion (P) of U.S. adults who, for example, are likely or very likely to have their organs donated. For estimation of P for the Asian, Hispanic, or Native American groups at the national level, the sample size will be 500 and, assuming a maximum design effect of 1.25, the sampling error will be less than 5percent even under the most conservative assumption of P=50percent. It will be comparable to the precision of estimates for the African American group.

Weighting of Sample Data. The sample data will be weighted to minimize bias in the survey based estimates. The weights will be necessary to correct for unequal selection probability and also to adjust for the effects of non-response. Sampling weights will be attached to each survey record and the final weight assigned to any case will be the product of the weights generated at several stages of the weighting process. The basic weighting steps for the weighting of the Native American, Asian and Hispanic samples will be similar to those described above for African Americans. The difference will be the fact that the sample will be generated from the Gallup WBI survey instead of the Gallup Panel. The probability weight assigned to any sampled unit for this sample will be the product of the (i) 'WBI survey weight' and (ii) the inverse of the selection probability of the unit in the Asian, Hispanic, or Native American sample to be drawn from the Gallup WBI survey. The next weighting step will consist of weighting adjustments for survey non-response. A significant amount of information on demographic variables (age, gender, race, ethnicity etc.) will be available for non-respondents from the WBI survey. As a result, it will be possible to construct suitable non-response adjustment cells and correct for any bias due to non-response. Finally, if necessary, an additional post-stratification weighting step will be used to make the final sample reflect the population it is intended to represent. The target data for post-stratification weighting, if used, will be obtained from Census or CPS.

Non-response Analysis. Survey based estimates for this study will be weighted to minimize any potential bias that may be associated with unit level non-response. For the Asian, Hispanic, and Native American samples, a significant amount of information will be available from the WBI survey data both for respondents and non-respondents. As a result, it will be possible to examine the non-response pattern within various demographic subgroups and, on that basis, construct suitable non-response weighting adjustment cells using variables that are available for both groups. In addition, if found necessary, the respondents to survey may be split into two groups: (i) early or 'easy to reach' and (ii) late or 'difficult to reach' respondents. The total number of calls required to complete an interview will be used to identify these groups. This comparison will be based on selected key questions from the main survey and on the assumption that the latter group may in some ways resemble the population of non-respondents. The goal of the

analysis plan will be to assess the nature of the non-response pattern in the main survey.

2. <u>Information Collection Procedure</u>

The mode of data collection will be telephone based on a Computer Assisted Telephone Interviewing (CATI) system. Interviewing will be conducted during weekday evenings and on weekends to increase the likelihood of finding respondents at home. A 5 plus 5 call design (up to five calls to establish human contact and then a maximum of five calls to complete the interview with the selected respondent) will be employed. Respondents who decline to be interviewed ("soft refusals") will be called back on a different day and a refusal conversion will be attempted. The interviews will be conducted in English and Spanish.

As mentioned earlier, the telephone sample for this study will include both landline and cell phones. Respondents reached on cell phones (landlines) will be interviewed regardless of whether they also have access to landline (cell phones). For both landline and cell phones, the geographic location of the respondent will be determined based on respondents' self-reported response to a question on location (like 'what is your zip-code?'). For respondents reached on cell phones, questions asking about cell phone use and status (cell only, dual user cell mostly, etc.) will be asked to be able to carry out weighting of the sample data appropriately.

3. <u>Methods to Maximize Response Rates</u>

In order to maximize response rates, Gallup will utilize a comprehensive plan that focuses on (1) having a call design that will ensure call attempts are made at different times of day and different days of the week to maximize contact rates, (2) conducting an extensive interviewer briefing prior to the field period that educates them about the content of the survey as well as how to handle reluctance and refusals, (3) having strong supervision that will ensure that high quality data are collected throughout the field period, (4) utilizing troubleshooting teams to attack specific data collection problems that may occur during the field period, and (5) customizing refusal aversion and conversion techniques.

To maximize the response rate to the survey, the data collection methodology will include the following:

- Calling up to 10 times to reach a household and complete the interview.
- Calling at alternate times of the day and on weekends to reach all respondents.
- Having a carefully designed introduction and promise of confidentiality to increase trust and salience.
- Having a questionnaire designed to increase completion and minimize item non-response.

4. <u>Tests of Procedures</u>

As mentioned earlier, the research planned for 2011 is intended to extend and expand upon prior surveys on organ donation especially the one conducted for HRSA by the Gallup Organization in 2005. A majority of the items (more than 80 percent) included in the current survey were included in the 2005 survey. In some cases, minor revisions have been made. In addition, initial

cognitive tests of 9 respondents were conducted using the current questionnaire for flow and clarity. No separate pilot study was therefore considered necessary.

5. <u>Statistical Consultants</u>

This study methodology and overall sampling design was developed through a contract with Gallup, which has expertise in developing sampling designs for telephone surveys, including the kinds of minority and ethnic group oversamples required by the current study. Gallup was selected under a competitive contract and will perform sample selection, data collection, analysis of the results, and writing of the report for public distribution.

The table below provides the names, telephone numbers, and email addresses of Gallup personnel who developed the statistical aspects of the design, finalized the data collection plan, and will be primarily responsible for collecting, analyzing, and reporting on the data. It also includes the name, telephone number and email address of the HRSA COTR who will provide oversight for this project.

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	<u>Company/</u>		
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Reference

Robert J. Casady and James, M. Lepkowski (1993). Stratified Telephone Survey Designs. *Survey Methodology*, 19, 103-113.

O'Rourke, D. & Blair, J. (1983): Improving Random Respondent Selection in Telephone Surveys. *Journal of Marketing Research*, 20, 428-432.

Kennedy, Courtney (2007): Evaluating the Effects of Screening for Telephone Service in Dual Frame RDD Surveys, *Public Opinion Quarterly*, Special Issue 2007, Volume 71/Number 5: 750-771.